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Human rights and bioethics

Report of the Secretary-General*

I. Introduction

1. At its fifty-seventh session, the Commission on Human Rights, in its resolution 2001/71 took note of the report of the Secretary-General on human rights and bioethics (E/CN.4/2001/93) and invited the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), the Office of the United Nations High Commissioner for Human Rights and the other United Nations bodies and specialized agencies concerned to report to the Secretary-General on the activities conducted in their respective areas to ensure that the principles set forth in the Universal Declaration on the Human Genome and Human Rights are taken into account. The Economic and Social Council, in its decision 2001/273 of 24 July 2001, endorsed the resolution of the Commission.

2. The Commission also invited the Secretary-General to draw up proposals, on the basis of these contributions for consideration by the General Assembly at its fifty-sixth session, concerning ways to ensure proper coordination of activities and thinking on bioethics throughout the United Nations system and to consider establishing a working group of independent experts from, inter alia, UNESCO, WHO and the World Intellectual Property Organization (WIPO), which would reflect, in particular, on the possible follow-up to the Universal Declaration on the Human Genome and Human Rights, and which would report to the Secretary-General within a period to be determined by him.

3. By communications dated 7 and 8 June 2001, the Secretary-General invited Member States and the relevant United Nations bodies and specialized agencies to submit their contributions, pursuant to that resolution, to the Office of the United Nations High Commissioner for Human Rights by 29 June 2001.

4. By 27 July 2001, replies had been received from the Governments of Costa Rica, Cuba, Mexico, Nicaragua, Switzerland and the United States of America, and from UNESCO, WHO and the International Labour Office (ILO). The United Nations Population Fund (UNFPA) replied that it is currently reviewing its position regarding this complex subject.

* The date of issuance of the present report is due to the late submission of contributions from Governments and United Nations agencies.

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II. Replies received from Governments

5. The Government of Cuba referred to the importance of efforts made within the United Nations system to promote a life sciences ethic and, in particular, the aim of the genuine realization of the right of all individuals and peoples, without discrimination of any kind, to enjoy the benefits of scientific and technological progress. The Government highlighted the fact that Cuba was a sponsor of General Assembly resolution 53/152 of 9 December 1998, which endorsed the Universal Declaration on the Human Genome and Human Rights, adopted by the General Conference of UNESCO on 11 November 1997, and expressed its support for any effort made towards a peaceful use of science and the international cooperation needed to guarantee it. Additional comments provided by the Government of Cuba will be included in the report of the Secretary-General to the fifty-ninth session of the Commission on Human Rights.

6. The Governments of Switzerland and the United States of America indicated that they had no proposal, at this stage, regarding the coordination of the activities of the United Nations on bioethics.

7. The replies received from Costa Rica, Mexico and Nicaragua addressed various aspects of the Commission resolution but did not include any specific proposal pertaining to the core subject of this report, namely, the coordination of activities and thinking on bioethics throughout the United Nations system. Therefore, the relevant comments contained therein will be reflected in the report of the Secretary-General to the fifty-ninth session of the Commission on Human Rights.

III. Replies received from the specialized agencies of the United Nations

8. UNESCO referred to the International Bioethics Committee and the Intergovernmental Bioethics Committee, highlighting their membership and functions. It recalled the work of the International Bioethics Committee since 1993 in preparing the Universal Declaration on the Human Genome and Human Rights, noting that this was adopted by the General Conference of UNESCO in 1997 and endorsed by the General Assembly in 1999. With regard to the invitation by the Commission on Human Rights to the Secretary-General to consider establishing a working group of independent experts, UNESCO was of the view that the establishment of a high-level group of policy decision makers would be potentially the most constructive way forward.

9. At the conclusion of its second session, held in Paris from 14 to 16 May 2001, the Intergovernmental Bioethics Committee adopted a series of recommendations. The attention of the Office of the High Commissioner was drawn to recommendation 17, in which the Intergovernmental Bioethics Committee supported the initiative of the Director-General of UNESCO proposing the creation of an inter-agency committee with the task of improving coordination of the activities in bioethics of different organizations and invited him to act on it as soon as possible (see annex I). The Director-General took the initiative of convening a one-day meeting, held at UNESCO headquarters, on Monday 17 September 2001, with a view to establishing this inter-agency Committee.

10. WHO provided details on its activities, which aim to ensure that the principles set forth in the Universal Declaration on the Human Genome and Human Rights are taken into account. On the one hand, a health and human rights strategy is being developed for the organization as a whole, with a view to integrating human rights principles and standards in the design, implementation, monitoring and evaluation of health policies and programmes. On the other hand, bioethics is a cross-cutting subject that spans a range of ongoing WHO programmes, including health research involving human subjects, ethical and social issues raised by the new scientific and technological advances in genetics and related biotechnology, ethical dilemmas in the testing and introduction of vaccines and ethical issues in health resource allocation.

11. Bioethics and human rights are two disciplines often pursued in isolation while having similar ends. Bioethical contributions to resource allocation and equity might inform the bodies charged with responsibility for human rights monitoring with regard to the realization of the right to health. There is a potential usefulness in applying human rights norms to such fields as research on human subjects and ethical issues raised in genomics. Such an initiative could be undertaken and developed through cooperation

between the United Nations staff with professional experience in the relevant fields and professionals and community representatives from various countries.

12. Among the examples of its specific work in areas involving bioethics, WHO referred to its inter-cluster initiative, within the Department of Management of Noncommunicable Diseases, to develop a strategic plan with specific topics that could be addressed by WHO in respect of ethical, legal and social issues related to genomics, with an emphasis on developing countries. Reference was also made to the ethics in health research involving human subjects (the Global Forum for Bioethics in Research), the pursuit of equity in health resource allocation and WHO training programmes in the ethical review of research throughout the developing world (see annex II).

13. Referring to its bioethics-related activities, the International Labour Office drew attention to two of the ILO codes of practice, entitled *Protection of Workers' Personal Data*, adopted in 1996, and *Technical and Ethical Guidelines for Workers' Health Surveillance*, adopted in 1997. Reference was made to specific provisions of both codes of practice. The code on the protection of workers' rights states that genetic screening should be prohibited or limited to cases explicitly authorized by national legislation (para. 6.12). The guidelines specify that at present, it is generally believed that genetic screening in relation to work is a disproportionate infringement of individual rights. Current knowledge is not sufficient to warrant its use for an occupational health purpose (para. 3.20).

IV. Office of the United Nations High Commissioner for Human Rights

14. In paragraph 5 of resolution 2001/71, the Commission on Human Rights invited the United Nations High Commissioner for Human Rights to pay all due attention to the question of bioethics within her area of competence. Accordingly, the High Commissioner will organize a consultation of high-level experts on human rights and bioethics to discuss the implementation of the Universal Declaration on the Human Genome and Human Rights. The Office of the High Commissioner is currently engaged in consultations with United Nations specialized agencies to improve coordination on the question of human rights and bioethics.

V. Coordination of activities

15. In paragraph 4 of resolution 2001/71, the Commission invited the Secretary-General to draw up proposals concerning ways to ensure proper coordination of activities and thinking on bioethics throughout the United Nations system.

16. The Secretary-General has received contributions from the specialized agencies reflecting a wide range of activities being carried out by each agency. They also provide useful information on consultations being carried out to ensure cooperation and coordination within the United Nations system. The Secretary-General realizes that there is an enormous potential for and need to consolidate coordination and cooperation between the Office of the High Commissioner, the different United Nations human rights bodies and other specialized agencies within the United Nations system. From the perspective of the United Nations reform programme, a central place should be assigned to human rights in this context to ensure their mainstreaming within the whole set of United Nations activities.

17. In the light of the above, it will be necessary to assess whether the establishment of a working group of independent experts, as suggested by the Commission on Human Rights, or a high-level group of policy makers, as proposed by UNESCO, are the best way to ensure effective cooperation and coordination of activities and further reflection and follow-up on the implementation of the Universal Declaration on the Human Genome and Human Rights.

18. Given the work carried out by UNESCO in its ongoing initiatives, its proposal offers a useful way both to make full and efficient use of the expertise within the United Nations system and to ensure incorporation of the concerns of the United Nations human rights organs in policy decision-making.

19. The Secretary-General is of the view that responsibility for further action be allocated to the bodies or agencies that have already developed programmes of activities in this field. Therefore, he would recommend that UNESCO and WHO, in cooperation with the Office of the High Commissioner, be requested to carry out further consultations with other United Nations bodies and the specialized agencies on the best ways to ensure effective cooperation and coordination of activities and further

reflection and follow-up on the implementation of the Universal Declaration on the Human Genome and Human Rights. Such consultations should consider, inter alia, the inter-agency committee proposed by UNESCO, the working group of independent experts, as suggested by the Commission on Human Rights, as well as the mandate of such bodies, and the outcome of the consultations should be included in a report to the General Assembly at its next session.

Annex I

Response of the United Nations Educational, Scientific and Cultural Organization

The International Bioethics Committee is composed of 36 top-level specialists, from all regions, in the fields of medicine, biology, genetics, law, philosophy, social and human sciences, who are appointed by me in their personal capacities. In 1993, the Committee was entrusted with the task of preparing an international instrument on the human genome, the Universal Declaration on the Human Genome and Human Rights, which was adopted by the General Conference of the United Nations Educational, Scientific and Cultural Organization (UNESCO) in 1997 and endorsed by the General Assembly of the United Nations in 1998. The Declaration is the first worldwide instrument in the field of biology, medicine and genetics. The International Bioethics Committee has favoured a pragmatic approach based on the latest advances in genetics and its applications. It encourages synergy among all national ethics committees worldwide and all associations involved in this field, thereby ensuring follow-up to the Declaration. Research on embryonic stem cells is currently one of its main concerns, which has resulted in the publication of its report on the use of embryonic stem cells in therapeutic research. The Intergovernmental Bioethics Committee is composed of the representatives of 36 Member States elected by the General Conference of UNESCO.

Notwithstanding the notable successes achieved in this area, it is clear that, as has been documented in the proceedings of these bodies, many obstacles remain. In particular, specific issues, such as the use of embryonic stem cells in therapeutic research, and the intellectual property issue related to genomics, and more generally to biotechnologies, are still unresolved. Such obstacles, which are fundamentally of a political or institutional nature, may not be solved by the creation of a new working group of independent experts, as recommended by Commission on Human Rights resolution 2001/71. A new initiative, such as the establishment of a high-level group of policy decision makers, may potentially be the most constructive way forward.

If, moreover, the idea of preparing a universal text on bioethics were taken up, UNESCO could take the lead and entrust the operation to the International Bioethics Committee and the Intergovernmental Bioethics Committee, for reasons of efficiency and in order to avoid duplication of efforts and the wasting of precious resources. Taking advantage of these existing bodies, consultations are proceeding in this connection. The Intergovernmental Bioethics Committee has already been consulted, at its second session, held in Paris from 14 to 16 May 2001, and the International Bioethics Committee and the Executive Board of UNESCO will soon be consulted also in order to ascertain whether there is general support for such a standard-setting activity within the scientific community and from Member States.

It is clear that all these endeavours would require strong inter-agency cooperation, involving, in addition to UNESCO, the Office of the United Nations High Commissioner for Human Rights, the Food and Agriculture Organization of the United Nations (FAO), the International Labour Organization (ILO), the United Nations Children's Fund (UNICEF), the World Health Organization (WHO), the World Intellectual Property Organization (WIPO) and other sister agencies and institutions. Accordingly, it would be appropriate to establish an inter-agency committee on bioethics, as is recommended in the Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights, endorsed by the General Conference of UNESCO at its thirtieth session.

Annex II

Response of the World Health Organization

The World Health Organization (WHO) welcomes the opportunity to report to the Secretary-General on the activities conducted by the Organization to ensure that the principles set forth in the Universal Declaration on the Human Genome and Human Rights are taken into account and to suggest ways in which proper coordination of activities and thinking on bioethics could be ensured throughout the United Nations system.

WHO has increased its level of activity in recent years in both fields. Focal points have been established through recruitment of individuals with professional backgrounds in these fields.

The Organization's work in bioethics spans a range of programmes, including:

- Ethical issues in health resource allocation;
- Ethics of health research involving human subjects;
- Ethical and social issues raised by new scientific and technological advances in genetics and related biotechnology;
- Ethical dilemma in the testing and introduction of vaccines;
- Allocation of the burdens of home care.

WHO construes bioethics broadly and seeks to illuminate the ethical choices that arise in areas of greatest need, in addition to those posed by scientific advances.

In the field of health and human rights, WHO is pursuing two mutually reinforcing tracks of work. The first is to develop a health and human rights strategy for the organization as a whole. The second is to expand technical work to demonstrate the practical application of human rights in the health field. The three overall areas of work identified in the evolving strategy are:

- Developing a health and human rights approach within WHO, which entails integrating human rights principles and standards in designing, implementing, monitoring and evaluating health policies and programmes;
- Developing the capacity of Member States to integrate human rights in health;
- Advancing the international human rights agenda relating to health.

Although bioethics and human rights are often pursued in isolation, they have similar ends. Human rights refer to an internationally agreed upon set of principles and norms embodied in international legal instruments, while bioethics is seen in terms of reflection on past traditions and beliefs and the attempt to reach reasoned consensus in the midst of the dilemmas posed both by new technology and by re-evaluation of current health practices in the light of changing social norms.

WHO has instituted a series of seminars covering both bioethics and health and human rights and there is frequent consultation among staff in both fields.

The notion that there should be a division of labour between bioethics and human rights has been more firmly based in practice than in theory. Different people tend to be drawn into these two fields, whether at WHO or elsewhere, and those who work in one of them do not always keep up with developments in the other. This has been true worldwide in Governments, non-governmental organizations and in academia, and it is widely recognized that the negotiation of the terms of cooperation between these fields is an important task for the near future.

One area in which collaboration may be particularly fruitful is the right to health, where bioethical contributions to resource allocation and equity may inform the bodies charged with responsibility for human rights monitoring. There can be little doubt of the potential usefulness of applying human rights norms to such a field as research on human subjects and ethical issues raised in genomics, but these need to be worked out over time, preferably through cooperation between staff whose professional backgrounds span these fields, in consultation with professionals and community representatives from many countries.

As an example of a specific work area, within the broad field of bioethics, the Department of

Management of Noncommunicable Diseases has been focusing on genomics. The Department is coordinating an inter-cluster initiative to develop a strategic plan with specific topics that WHO can address in the area of ethical, legal and social issues related to genomics, with an emphasis on developing countries. The Department's role is to ensure that the work plan and agenda incorporate all of the relevant activities of WHO both at Headquarters and in the regional offices. The process of drafting this work plan started in July 2000 when a meeting was held to discuss future directions for WHO in human genetics.

A second example of a bioethical subject that has received much attention at WHO is the ethics of health research involving human subjects. Research projects, in particular those sponsored by Western firms and Governments and carried out in developing countries, have become highly controversial in recent years. WHO has formed a partnership, the "Global Forum on Bioethics in Research", with several other health research organizations, including the National Institutes of Health and the Centers for Disease Control and Prevention (United States of America) and the Medical Research Councils of the United Kingdom of Great Britain and Northern Ireland and South Africa. This Forum meets annually. Moreover, four WHO programmes carry out training workshops on the ethical review of research throughout the developing world.

A third example is the pursuit of equity in health resource allocation. This is a topic addressed within the spheres both of bioethics and health and human rights. WHO's effort in bioethics includes an ambitious research programme involving over 16 philosophers and economists worldwide.